

HOME PARENTERAL **NUTRITION** AWARENESS WEEK

PARTICIPATION & ACTION GUIDE



HPN Awareness Week
Presented by:



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PURPOSE

HPN Awareness Week is a time to share what life with home parenteral nutrition actually looks like and to connect people to practical support, education, and resources. This guide brings together ideas, tools, and ways to participate across the HPN community.

You do not need to do everything. Choose what fits your role and your capacity.

AWARENESS TO ACTION

Awareness matters, but awareness alone does not change daily life for people on HPN. HPN Awareness Week focuses on participation, education, connection, and action.

Action can include:

- Sharing lived experience so others understand HPN
 - Connecting people with practical resources
 - Strengthening education for patients, caregivers, and healthcare professionals
 - Supporting safer care and transitions
 - Identifying gaps in access and support
 - Bringing consumers, clinicians, and partners together to improve care.
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EASY WAYS TO PARTICIPATE

These options require minimal time and effort:

- Share Oley's HPN Awareness Week graphics
 - Use #HPNAwarenessWeek
 - Tag @OleyFoundation and people or organizations you want to recognize
 - Share one HPN story, fact, resource, tip, or lived experience
 - Invite someone who may not understand HPN to learn more
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LIGHTED LANDMARKS

Landmarks across the country will light up in recognition of HPN Awareness Week, honoring the individuals and families who live with home parenteral nutrition every day. A list of participating landmarks and photos will be shared throughout the week.

Sharing these images helps shine a light on HPN and bring greater understanding beyond the nutrition support community. When someone asks why a landmark is lit, tell them it's in honor of HPN Awareness Week and the community that makes life on HPN possible.

OLEY RESOURCES TO SHARE

[Oley.org/HPN](https://oley.org/HPN)

Awareness often leads to questions. These resources are available when you need them:

- [Parenteral Lipid Discussion Guide](#)
- [Restaurant and Bathroom Cards](#)
- Transfer of care checklist: [English](#) / [Spanish](#)
- CVAD Discussion guide: [English](#) / [Spanish](#)
- Transition Care Checklist: [English](#) / [Spanish](#)
- Guide to keeping your IV safe and infection-free: [English](#) / [Spanish](#)
- [Peer Support and Connection Through Oley](#)

[Social Media Frames](#)

Create your "Proud Supporter of HPN Awareness Week" social media frames to show you are part of the feeding tube community. To participate, select the frame, add it to a photo, and share it on your social media channels.

Then tag @OleyFoundation, use #HPNAwarenessWeek and #HPNAW26, and invite others in the home parenteral nutrition community to add the frame to their own posts.



[Get Free HPN Buttons](#)

We now have buttons available to request and they're completely free. Claim yours now at, oley.org/hpn.



SPECIFIC WAYS FOR COMMUNITY MEMBERS TO PARTICIPATE

HPN Consumers and Caregivers

Participate in ways that feel comfortable and authentic to you.

You could:

- share what an HPN day looks like
- share something you wish others understood about HPN
- share a tip, adaptation, or routine that helps you; talking about what HPN allows you to do
- share an Oley resource with your healthcare team
- recognize someone who has supported your HPN journey
- or talk about something you would like to see improve in HPN care

Prompts for social posts

- This is how I eat ...
- HPN helps me ...
- One thing I wish people knew ...
- I am more than HPN ...
- One supply that helped me is ...
- A life hack I learned ...

Caregivers, Parents, and Family Members

Your perspective helps others understand the planning, problem-solving, and support behind nutrition support.

You might:

- Share what caregiving on HPN looks like day to day
- Explain how HPN supports safety, growth, or stability
- Acknowledge a clinician, supplier, or support person who helped you

Clinicians and Healthcare Professionals

Healthcare professionals play an important role in helping people on HPN receive safe, informed, patient-centered care. HPN Awareness Week is an opportunity to share expertise while also learning directly from consumers and caregivers

.Actions could include:

- Sharing an evidence-based HPN practice
 - Highlighting patient education or discharge readiness
 - Sharing Oley resources with colleagues
 - Partnering with patient organizations; collaborating across interdisciplinary teams
 - Amplifying lived experience
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Industry and Corporate Partners

Industry participation helps extend reach and reinforce shared responsibility.

You can:

- Share stories of how your team supports the HPN community
- Highlight products, services, or innovations that improve daily life
- Help educate others about access and supply challenges
- Amplify consumer and caregiver voices
- Partner with consumers, clinicians, advocates, and other organizations to identify solutions

Friends, Allies, and the Broader Community

Support does not require expertise. We encourage everyone to participate in HPN Awareness week.

To get involved:

- Learn about HPN and nutrition support
- Share awareness graphics
- Challenge stereotypes when you see them
- Listen to people who live this experience

STAY CONNECTED

Ready to join the Oley community?
Visit Oley.org to become a member.

Membership is free.

If you have questions or need assistance, reach out to us at info@oley.org.

You can also follow Oley on social media to stay connected.



ABOUT OLEY

Values: We are patient-centered, science-based, and solution-oriented.

Mission: To enrich the lives of those living with home IV nutrition or tube feeding through advocacy, education, community, and innovation.

Vision: Oley envisions a world where patients are united, supported, and empowered to thrive on home nutrition support.

Key Strategic Pillars

- **Advocacy.** We are the voice to, of, and for, the people on home nutrition therapy and their caregivers.
- **Education.** We create and disseminate patient-focused best practices for home nutrition support.
- **Community.** We unite, support, and empower everyone involved in home nutrition therapy in an inclusive, diverse, and accessible environment.
- **Innovation.** We support the patient-centered improvement and evolution of nutrition therapy to enable patients to live the best life possible.

What we do

- We advocate for systemic issues of patient safety and access
- We empower people who cannot get enough nutrition from eating alone and rely on feeding tubes or IV nutrition to thrive.
- We study and design the patient journey, identifying challenges and creating patient-centered solutions that include lived experience with clinical expertise.
- We build bridges between those with lived experience, clinical expertise, and creative solutions and value all voices.
- 90% of all programs and resources will be directed towards the heart of the mission while honoring the whole person experience

Who We Serve and Work With

Oley brings together people living with HPN, families and caregivers, clinicians, healthcare providers, industry partners, advocates, and other organizations. By combining lived experience with clinical and professional expertise, we work to strengthen education, improve access and safety, build connections, and support a better quality of life for people who rely on HPN.

Supporting Life on HPN

HPN is more than a medical therapy—it becomes part of everyday life. Oley supports individuals and families as they navigate the practical, emotional, and medical realities of living with HPN through education, connection, advocacy, and resources shaped by the people who understand this experience firsthand.

ADVOCACY ACTION ALERT

PROTECT ACCESS TO HOME PARENTERAL NUTRITION

Home parenteral nutrition (HPN) is life-sustaining medical therapy for people who cannot safely or adequately meet their nutrition needs through the digestive system. Access to HPN depends on a coordinated system of specialized pharmacies, supplies, equipment, clinical expertise, and ongoing support.

Yet coverage, reimbursement, and access challenges can make it difficult for people who rely on HPN to receive the care and services they need at home. These challenges can affect patients, families, clinicians, and the providers responsible for safely delivering this complex therapy. Oley continues to advocate for policies that support reliable access to home parenteral nutrition and the services needed to provide it safely.

HPN Awareness Week is an important opportunity to speak up. Sharing your experience can help policymakers better understand why access to HPN matters and how gaps in coverage or services affect real people and families.

- Contact your elected officials and ask them to support reliable access to home parenteral nutrition
- Share how access, coverage, or reimbursement challenges have affected you or your loved one
- Explain why the supplies, pharmacy services, clinical support, and expertise behind HPN are essential
- Add your voice to help protect access to safe, sustainable HPN care at home

This resource is provided for educational purposes only and is not intended as medical advice. It outlines general expectations based on current evidence-based guidelines, but individual care protocols may vary depending on hospital policies, provider judgment, and patient-specific needs.

Always consult your healthcare team for personalized medical guidance and before making any changes to your care plan.

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